

Perceived Familial Risk of Cancer: Health Concerns and Psychosocial Adjustment

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ABSTRACT. This study explored the psychosocial morbidity and health concerns accompanying individuals' perceived increased risk of cancer. Lazarus and Folkman's concept of stress and coping guided the study. In a Familial Cancer Program, 78 patients were divided into two groups: 39 with and 39 without a cancer diagnosis. Questionnaires completed in the clinic before a risk evaluation included Spielberger's Trait Anxiety Scale, the Medical Outcome Study Questionnaire, the Bipolar Profile of Mood States (POMS-BI), and an investigator-designed open-ended questions reviewed by a panel of experts. Data analyses using descriptive statistics and Wilcoxon rank sum tests revealed differences between qualitative and quantitative interpretations

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of risk: Patients' perception of a high lifetime risk ranged from 16% to 88%. A favorable median global mood score was found on the POMS-BI, whereas a distress-specific question revealed an increased level of stress caused by the person's cancer risk. Trait anxiety correlated significantly with most health and psychosocial variables ($r = -.22$ to $.67$). Few differences between the two groups were found regarding health concerns and psychosocial variables. Patients identified emotional and family concerns and their uncertain situation most often as being difficult in dealing with their risk, and they identified information, support, and screening most often as being helpful. The findings provide guidance for addressing psychosocial morbidity in members of cancer-prone families. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-342-9678. E-mail address: <getinfo@haworthpressinc.com> Website: <<http://www.haworthpressinc.com>>]

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Familial cancer syndromes and predictive genetic testing have received significant attention in the last decade because of extraordinary advances that have occurred in the molecular biology of these disorders. However, an understanding of the psychosocial, legal, and ethical dimensions of familial cancer risk has lagged behind. The focus of the present study was on psychosocial concerns. Specifically, its purpose was to explore the psychosocial morbidity and health concerns accompanying individuals' perceived increased risk of cancer.

REVIEW OF THE LITERATURE

Data regarding the health and psychosocial concerns of individuals at increased familial risk of cancer are limited. The existing literature focuses primarily on the concerns of women at increased risk for familial breast cancer.

Perceived Health Risk

Many women in familial risk-assessment programs are self-referred. Despite this apparent acknowledgment of their perceived increased risk of cancer, many of these women do not know either their own lifetime risk of developing breast cancer or the lifetime risk of women in general (Evans et al., 1994). They report either an average or below average risk (Kash et al.,

1992; Stefanek & Wilcox, 1991) or, more commonly, overestimate their risk (Lerman et al., 1995). In fact, even after counseling, these women are often unable to report their correct lifetime risk (Evans et al., 1994; Lerman et al., 1995; Lloyd et al., 1996).

Little is known about which factors influence the perception of risk. Age is inversely associated with perceived risk of breast cancer (Vernon et al., 1993), whereas an increased number of affected family members is associated directly with increased perceived risk of breast cancer (Evans et al., 1993).

Psychosocial Morbidity

In general, the burden of seeing oneself as being at increased risk for cancer is vividly illustrated by the report that such individuals identify the risk of disease as equivalent to the risk of death (Kelly, 1992). However, the details of this psychological morbidity are only beginning to emerge. Psychological distress is high among women at increased risk for breast cancer (Kash et al., 1992; Lerman & Schwartz, 1993; Lerman et al., 1993). Kash et al. (1992) reported that mean psychological distress scores were almost one standard deviation above the normed mean. In contrast, Lloyd et al. (1996) found that the risk of breast cancer was not predictive of global psychological morbidity but was associated with an increased level of cancer-specific distress.

Of clinical concern is that women with high levels of psychological distress are less likely to follow recommendations concerning mammograms or breast self-examinations (Kash et al., 1992; Lerman & Schwartz, 1993). Although women with intrusive thoughts also are less likely to have periodic mammograms, they practice breast self-examinations excessively (Lerman, Kash, & Stefanek, 1994). Lerman and Schwartz (1993) suggested that differences found in the associations between psychological distress and adherence to cancer screening recommendations may be a consequence of specifically what one measures. Global measures developed for psychologically distressed populations reveal a negative association with adherence to screening, whereas specific measures developed to reveal distress related to breast cancer show a positive association between distress and adherence.

Several factors influence psychosocial outcomes of women at increased risk for breast cancer. Age is one factor—women younger than 29 years have the highest levels of global psychological distress when compared with women older than 50 years, and older women demonstrate more intrusive thoughts than younger women do (Lerman, Kash, & Stefanek, 1994). In addition, low levels of social support, use of denial, higher levels of perceived risk of cancer, and identification of an increased number of barriers to screening are associated with increased levels of psychosocial distress (Kash et al., 1992).

Patients have identified several useful factors in adapting to an increased risk of cancer. These include possessing accurate factual information about one's situation (Chalmers, Thomson, & Degner, 1996; Kelly, 1992), experiencing a sense of supportiveness from others, and having the ability to communicate openly about concerns with family, friends, and health care professionals (Chalmers, Thomson, & Degner, 1996). Support promotes adjustment by validating feelings and putting the risk of cancer in perspective (Chalmers, Thomson, & Degner, 1996). Accurate information increases personal control by providing knowledge of experiences that may be ahead and by permitting accurate perceptions of risk. Unfortunately, many women at increased risk for breast cancer reported that the information they received was insufficient, inaccurate, and fragmented (Chalmers, Thomson, & Degner, 1996). Individuals at increased risk for a variety of cancers reported a wide range of unmet educational needs (Mahon & Casperson, 1995).

Although the psychosocial dynamics operating in people at increased risk for cancer have begun to unravel, health care professionals have much to learn before they can manage such patients in an optimal fashion. In the present study, we explored people's appraisals, health concerns, and psychosocial morbidities as well as the influence of trait anxiety on the aforementioned variables.

The framework for the study was Lazarus and Folkman's conception (1984) of stress and coping in which individuals' appraisal and resulting perception of their situation play a key role in their coping process was used to guide the study. Antecedent variables in the study that influence appraisal include such environmental or situational factors as age, educational status, occupation, medical diagnoses, and the number of family members with a cancer diagnosis. Identifying a correlation between anxiety and poor performance, Lazarus (1991) asserted that anxious people react to a threat with anxiety. Resources, such as marital status, would influence a person's appraisal. People who have been aware of their risk for a longer period would have time to reappraise the harm or threat involved in their situation. Lazarus and Folkman (1984) identified three major classes of adaptational outcomes: social functioning, morale, and somatic health.

We pursued answers to the following five questions:

- What do people attending a familial cancer program perceive as their risk of cancer and its effect on them and their family?
- What physical health and psychosocial morbidities accompany people's perception that they are at increased risk of cancer?
- What differences exist in psychosocial morbidities and health concerns between people with a cancer diagnosis and those without a cancer diagnosis?

- How do trait anxiety, demographic data, and medical information influence health concerns and psychosocial morbidities?
- What areas do people identify as being most helpful in adjusting to their increased risk of cancer?

METHOD

Procedure

The study cohort consisted of all individuals referred to the Familial Cancer Program of the Mayo Clinic in Rochester, Minnesota, which provides primary care to its surrounding communities and serves as a tertiary-care facility. Patients were self-referred or referred by a health care provider within or outside the Mayo system. The Familial Cancer Program is directed by a multidisciplinary team consisting of medical oncologists, geneticists, genetic counselors, and advanced-practice nurses. The program includes education and counseling about cancer risk, cancer risk reduction, effective screening methods, preventive options, and predictive genetic testing.

The majority of patients in the program are at increased risk for breast or ovarian cancer or both. Individuals considered to be at increased risk have (1) at least two first- or second-degree relatives with cancers related to the familial syndrome, (2) a first- or second-degree relative with double primary malignancies, or (3) a first-degree relative whose cancer was diagnosed when he or she was younger than 40 years.

All people referred to the Familial Cancer Program between July 1995 and February 1997 were asked to complete a packet of questionnaires after their clinical assessment but before a discussion about their risk status and recommendations for follow-up. They were given the option of not completing the questionnaires and were assured that their care would not be affected by their decision. Of the 95 patients referred to the program during this time period, 78 (82%) completed the majority of items in the packet and constituted our study cohort.

Instruments

The packet of questionnaires included select subscales from the Medical Outcome Study Questionnaire (MOS), Spielberger's Trait Anxiety Inventory (STAI), the Bipolar Profile of Mood States (POMS-BI), and a researcher-designed questionnaire. If a participant failed to answer more than 10% of the items on a scale, he or she did not receive a score for that scale.

Medical Outcome Study Questionnaire. The MOS consists of two global

dimensions: physical and mental health (Stewart & Ware, 1992). It measures 12 domains, 4 of which were used in the study: role functioning-emotional, social functioning, health perceptions, and health distress. Role functioning was measured by the Role-Emotional subscale, which addresses limitations in functioning as a result of emotional problems. Social functioning was measured by the following subscales: Social Function, Family Function, Family Satisfaction, Relationship Function, and Sexual Function. Health perceptions were measured by the Current Health, Prior Health, Health Outlook, and Health Concern subscales. Health distress was represented by the Health Distress subscale, which addresses psychological distress caused by one's health status.

Possible scores on the subscales range from 1 to 5, with the exception of scores on the Health Distress subscale, which range from 1 to 6, and on the Role Limitation subscale, which range from 0 to 3. A person's score is obtained by adding the raw scores and dividing by the number of items. High scores indicate the positive aspect of current health, prior health, health outlook, family satisfaction, family function, and relationship function. High scores on health concern, health distress, role limitations, social limitations, and sexual function reflect greater distress or limitations.

The MOS has documented reliability and validity. Internal consistency alphas reported in the literature and Cronbach's alphas observed in our study, respectively, on these subscales were as follows: role function, .83 and .81; social activity, .77 and .84; satisfaction with family life, .93 and .92; marital relationships, .83 and .89; sexual relationships, .90 and .96; health outlooks, .87 and .93; prior health, .74 and .80; health concern, .73 and .89; and health distress, .94 and .98. The validity of the domains was supported with the use of discriminate validity and factor analyses (Stewart & Ware, 1992).

Spielberger's Trait Anxiety Inventory. The STAI measures a person's proneness to anxiety that is regarded as intrinsic to the person's personality (Spielberger, 1983). The instrument has demonstrated reliability and validity. Test-retest correlations ranged from .65 to .86, and Cronbach's alphas have revealed a median coefficient of .90. Cronbach's alpha for the present study was .95. Validity was demonstrated by contrasting group comparisons and correlations with other measures of trait anxiety. Neuropsychiatric patients exhibited substantially higher scores than did normal subjects. Significant correlations were demonstrated between the STAI and other trait measures. Possible scores range from 20 to 80, with high scores reflecting higher levels of anxiety.

Bipolar Profile of Mood States. The POMS-BI was developed to measure the positive and negative aspects of six mood states (Lorr & McNair, 1988): composed-anxious, agreeable-hostile, elated-depressed, confident-unsure, energetic-tired, and clearheaded-confused. The Positive Affect subscale reflects

elated, energetic, agreeable, confident, clearheaded, and relaxed moods, and the Negative Affect subscale reflects hostile, unsure, anxious, depressed, confused, and tired moods. Items are scored and are normed to a population with a mean of 0 and a standard deviation of 1. High scores in the positive-affect domain reflect favorable affect, whereas high scores on the negative-affect domain reflect unfavorable affect.

Test-retest scores on the six mood states reveal correlations of .33 to .72, with no significant difference demonstrated in mean scores. Varimax rotation revealed two dimensions: positive affect and negative affect (Lorr & Wunderlich, 1988). Cronbach's alphas for the present study were .96 for positive affect and .96 for negative affect.

Researcher Questionnaire. The researcher-designed instrument in the packet included open-ended and categorical items eliciting the following information from participants: (1) demographic information, (2) their age when they first became aware of their cancer risk and the number of years they had been aware of the risk, (3) their rating of cancer risk on a qualitative scale rated as "No risk," "Low risk," "Average risk," "High risk," or "Extremely high risk," (4) their quantitative lifetime risk of cancer rated on a line scale ranging from 0% to 100%, (5) information on the impact of perceived increased risk on the participants and their families, and (6) open-ended questions asking participants what they found to be most difficult and most helpful in their efforts to adjust to their perceived risk status.

Participants were asked to rank how their perceived risk affected their self-esteem, satisfaction with their body's appearance, feelings of femininity or masculinity, level of stress, and emotional stability on a five-point scale ranging from greatly increased to greatly diminished. They also are asked to rank their stress on a five-point scale ranging from "Not stressful" to "Extremely stressful." Perceptions of their ability to cope are rated on a five-point scale ranging from "Not at all" to "Extremely well."

The questionnaire was reviewed for face validity by two physicians, two advanced-practice nurses, and a genetic counselor. After changes in wording were made, the same people reevaluated the instrument.

Data Analysis

Descriptive statistics were used to describe the study cohort. We used the Wilcoxon rank sum test to assess whether the health and psychosocial variables differed significantly between participants with cancer and those without cancer. The Fisher's exact test was used to assess whether a significant association existed between the health and psychosocial variables and various demographic and medical data. We calculated the correlations between trait anxiety and each health and psychosocial variable using Spearman's rank correlation coefficients.

Data related to perceived risk, effects on self and family, as well as identification of what was helpful and difficult in adjusting to perceived risk were reported only for participants without cancer. We took this approach because a cancer diagnosis would influence a participant's response to these questions. In addition, the responses of people with cancer might vary in relation to the time that is referenced, making it difficult to discern what was a result of their cancer diagnosis and what was a result of their high-risk status. Moreover, some people with cancer might respond to these questions in relation to their high-risk status before their diagnosis, whereas others might incorporate their cancer experience.

Data for the open-ended questions were analyzed by providing a code for each meaningful statement. The statements were then collated under themes, and the themes were collated under categories. All questionnaires were coded by one researcher. Ten percent of the questionnaires were recoded to determine coding agreement resulting in an intrarater reliability of 98%. Categorization of statements under themes and of themes under categories were discussed by two of the researchers. Consensus was reached on any area in which the researchers disagreed.

FINDINGS

The majority of participants were female, married, had at least some education after high school, and held blue-collar jobs (see Table 1). The participants' median age at diagnosis was 45 years ($M = 46$ years; $SD = 12.6$ years; range, 18-71 years). Half of the participants (39) had a personal history of cancer, including breast (23), ovarian (5), melanoma (3), uterine (2), osteosarcoma or Hodgkin's disease (1 each), or another cancer in addition to breast cancer (4). The median time since diagnosis was three years ($M = 6.4$ years; $SD = 9.1$ years; range, 0-45 years).

Participants with a history of cancer tended to be older than were those without such a history when referred to our program and when they became aware of their cancer risk. The number of years they had been aware of their increased risk for cancer was not found to be different (see Table 2).

The participants had one to six first-degree family members affected with some type of cancer or zero to four first-degree family members with a cancer related to the familial cancer syndrome for which the patient was being seen. The majority (62%) were seen because of an increased familial history of breast cancer. The next most frequent reason was a combination of two cancers (21%), followed by ovarian cancer or hereditary nonpolyposis colon cancer (6% each), double primary cancers (3%), and LiFraumeni and endometrial cancers (1% each).

Almost half (19) of the 39 participants without a prior history of cancer

TABLE 1. Demographic Characteristics of Participants With and Without a Cancer Diagnosis

Characteristic	With a Cancer Diagnosis (n = 39)		Without a Cancer Diagnosis (n = 39)	
	Number	Percentage	Number	Percentage
<u>Gender</u>				
Female	37	95	39	100
Male	2	5	0	0
<u>Education</u>				
Less than high school	0	--	1	3
High school	10	26	5	13
More than high school	26	67	27	69
Missing data	3	8	6	15
<u>Occupation</u>				
White collar	2	5	5	13
Blue collar	20	51	18	46
Homemaker or student	5	13	10	27
Unemployed, disabled, or retired	9	23	1	3
Missing data	3	8	5	13
<u>Marital status</u>				
Married	22	56	26	67
Single	6	15	4	10
Divorced or separated	6	15	3	8
Widowed	2	5	1	3
Missing data	3	8	5	13

TABLE 2. Additional Characteristics of Participants With and Without a Cancer Diagnosis: Age at the Time of the Study, Age When Became Aware of Cancer Risk, and Number of Years Since Becoming Aware of Risk

Variable	With a Cancer Diagnosis		Without a Cancer Diagnosis		Wilcoxon Rank Sum Test	p-Value
	Mean (SD)	Median (Range)	Mean (SD)	Median (Range)		
Age at time of the study	52 (13.3)	50 (21-76)	40 (9.6)	42 (17-60)	4.052	< .001
Age when first aware of cancer risk	34 (12.3)	32 (12-70)	28 (8.9)	27 (14-46)	2.398	.017
Number of years since aware of increased risk	17 (13.4)	12 (0-59)	11 (9.6)	10 (0-34)	1.641	.101

had sought medical care for their perceived increased risk of cancer before entering the Familial Cancer Program. Fifteen participants sought routine screening or mammograms, and 3 reported seeing their physician for a prophylactic mastectomy or oophorectomy. Only 1 participant reported seeing her physician about her family history.

Perceived Risk

Among the 39 participants without a prior history of cancer, 28 (72%) perceived themselves to be at high risk for the disease and 6 (15%) perceived themselves as being at extremely high risk. The remaining 5 participants (13%) perceived themselves to be at average risk. None of the participants identified him- or herself as being at low or no risk.

When the participants without a history of cancer were asked to quantify their lifetime risk, the relationship with their qualitative risk assessment varied greatly. The 5 participants who reported their cancer risk to be "average" cited their estimated lifetime risk as 25%, 30%, 35%, and 50%, respectively; 1 participant did not answer the question. The 28 participants who reported their risk as "high" translated that risk to cumulative probabilities ranging from 16% to 88% ($M = 58\%$, $SD = 19\%$, median = 56%). The 6 participants who perceived their risk as "extremely high" reported lifetime risks ranging from 75% to 100% ($M = 86\%$, $SD = 10\%$, median = 88%).

Impact of perceived risk. In response to an open-ended question, the participants who lacked a prior history of cancer reported that their perceived increased risk of cancer elicited a variety of emotional responses, mental processes, and coping skills. The most commonly cited personal responses were emotional stress and increased awareness of health (see Table 3). The same responses were reported as the ones that affected family members most often (see Table 4).

Most difficult and most helpful areas associated with increased risk. Participants without a history of cancer most frequently reported general concern for their family, concern for family members with cancer, uncertainty, and increased concern about personal health as difficult areas in adjusting to their perceived risk of cancer (see Table 5). These individuals said that information, support from family and friends, and screening were most helpful in dealing with their perceived cancer risk (see Table 6).

Health Concerns

Current health. Sixty-eight (89%) of the 76 participants who responded rated their current health as good, very good, or excellent, and 59 (78%) said their current health was the same as or better than it was one year ago. More

TABLE 3. Impact of Perceived Familial Risk on Individuals Without a Cancer Diagnosis ($n = 39$)^a

Category	Themes Under Designated Category	Number	% ^b
Increased awareness of health	Realizing the importance of diligent screening Increased awareness of mortality, symptoms, and factors that cause cancer	17	44
Emotional stress	Concerned but not overwhelmingly Feeling of doom Hopelessness	16	41
Sought information	Cancer prevention information Cancer information	9	23
Changed cognitive perspective	Appreciate life more Keep a positive attitude Learned fear is worse than cancer Determined to stick around Difficult to tolerate behaviors that increase risk of cancer	7	18
Healthy life-style changes	increased physical activity Increased healthy life-style changes	7	18
Concerned about family	Fears about children's future Concern about burden placed on family Worry that they have passed on a gene	5	13
Not much effect until a certain age	Wasn't concerned until older	2	5
Enhanced spirituality		1	3
Positive interpersonal changes	Increased awareness of relationships More compassionate	1	3
Others	Expect to get cancer	2	5
None/very little	Wonder about future	6	15

^aQuestion: What impact has knowledge of your increased risk for cancer had on you? (Include physical, mental, emotional, and interpersonal aspects.)

^bPercentages are greater than 100% because individuals may have entered multiple responses. All participants gave at least one response.

than 80% of the 77 who responded reported a moderate concern about their health. Twenty-five (32%) of the 77 participants who responded reported that they were uncertain about their future health, 9 (12%) reported unfavorable expectations about their future health, and 43 (56%) reported favorable expectations about their future health. The scores of participants with and without cancer on the current health and health concern subscales did not differ significantly. Participants who had had a cancer diagnosis had a signifi-

TABLE 4. Impact of Perceived Familial Risk on Families of Participants Without a Cancer Diagnosis ($n = 39$)^a

Category	Themes Under Designated Category	Number	% ^b
Emotional stress	Difficult for family members Worry about what the future will bring Fear	17	44
Increased awareness of health	Increased awareness of cancer and its effects Realizations of mortality Regular exam Cautious about physical changes Sought information about screening	12	31
Changed cognitive perspectives	Positive attitudes Appreciate life Try not to think of it Increased preparedness to accept presence of cancer	5	13
Positive interpersonal changes	Closer family relationships More emotional support	3	8
Not much effect until certain age	Wasn't concerned until older	2	5
Didn't know or failed to answer		4	10
None/minimal		10	26

^aQuestion: What impact has knowledge of your increased risk for cancer had on your family? (Include physical, mental, emotional, and interpersonal aspects.)

^bPercentages are greater than 100% because participants may have entered multiple responses.

cantly poorer health outlook than did those without a cancer diagnosis ($p = .030$).

Prior health and health distress. Participants without cancer reported better health in the past ($p = .002$) and less health distress ($p = .003$) than did those with cancer. Interestingly, when asked if they had ever been seriously ill, 21 of the 39 participants with a history of cancer said that the statement was "Mostly" or "Definitely" false, and 9 said that, on the average, emotional distress as a result of their health problems was present a "Good bit of the time" or "All the time" during the past four weeks.

Psychosocial Variables

Trait anxiety. Trait anxiety—prone to anxiety considered to be intrinsic to one's personality—was significantly related to most of the measured health and psychosocial variables ($r = -.22$ to $.67$), with the exception of health concern and social function. The strongest correlations were found between

TABLE 5. Increased Risk: Areas Identified by Participants Without a Cancer Diagnosis as the Most Difficult in Dealing with Increased Familial Risk ($n = 39$)^a

Category	Themes Under Designated Category	Number	% ^b
Concern for family	Impact on family Worry members will get cancer Not living long; effect on children and husband Increased risk for my children	6	15
Concern for family members with cancer	Observing other family members deal with cancer Loss of members	6	15
Uncertainty	Future possibilities Pain possibilities Survival rates Coping	6	15
Increased concern about health	Staying healthy Inevitability of cancer Concern about breast changes Needing to be watchful of signs or symptoms	6	15
Lack of knowledge	Approaches to decrease risk Cancer	5	13
Decision-making regarding prophylactic procedure		3	8
Emotional concern	Anticipating medical visits Ability to cope	3	8
Health care professional interactions	Minimizing concerns Conflicting information	2	5
Financial	Costs Insurance	1	3
Screening	Hassles Travel to clinic	1	3
Expressing emotions	Difficult letting others know	1	3
Relationship difficulties		1	3
Realization of mortality		1	3
Others	Body image if surgery necessary Being diagnosed with cancer	2	5
None		5	13
Did not answer		7	18

^aQuestion: What is the most difficult for you at this time in your adjustment to your cancer risk?^bPercentages are greater than 100% because participants may have entered multiple responses.

TABLE 6. Areas Identified by Participants Without a Cancer Diagnosis as Being Most Helpful in Dealing with an Increased Familial Risk of Cancer ($n = 39$)^a

Category	Themes Under Designated Category	Number	% ^b
Information	From health care professionals on risks and options Materials provided	18	46
Support from family and friends	Talking about risks Support provided	13	33
Screening	Routine screening	10	26
Cognitive restructuring	Staying positive Not focusing on it	6	15
Caring and competent health care providers	Having a knowledgeable health care professional to follow care Health care providers who don't dismiss concerns	6	15
Faith		5	13
Living a healthy life-style		5	13
Normalizing	Working	1	3
Others	Prophylactic surgical procedure Humor Increased awareness of body Supporting cancer research	4	10
Did not respond		7	18
None		1	3

^aQuestion: "What have you found helpful in your adjustment to your cancer risk?"^bPercentages are greater than 100% because participants may have entered multiple responses.

trait anxiety and positive affect ($r = -.58$), negative affect ($r = .65$), health distress ($r = .67$), and role limitations ($r = .52$).

Role limitations and social function. No evidence suggested a significant difference between the two groups of participants with regard to role limitations or social function. Twenty-two percent noted some level of disruption in their work in the last four weeks as a result of emotional problems, and 81% reported "moderate" to "extreme" difficulty with their social activities as a result of physical health or emotional problems.

Family functioning and satisfaction. Neither family functioning nor satisfaction with family life differed between participants in the two groups. "Very" to "Extremely high" levels of happiness with their family life was reported by 57 (76%) of the 75 who responded; only 5 (7%) rated their family functioning as "Not too happy" or "Very unhappy." In addition, 50 of the 75

responders (67%) reported levels of family satisfaction of "Very good" to "Excellent" in relation to understanding and support.

Sexual functioning and relationship function. No significant differences were found between participants with or without a cancer diagnosis on sexual or relationship function. Fifty-seven (80%) of the 71 participants who responded reported a positive relationship with their spouse or partner. However, 18 (26%) indicated "More than just a little" problem regarding the impact of their health on their sex life.

Mood states. The two groups did not differ significantly with regard to either negative or positive aspects of mood. The one-item question about the relationship between cancer risk and overall emotional stability indicated that the majority (61%) of the 74 participants who responded reported no impact on their emotional stability.

Stress. Twenty-four (65%) of the 37 participants with a previous history of cancer who responded and 16 (42%) of the 38 participants without a previous history of cancer who responded reported that their level of stress in life had "Increased" or "Greatly increased" as a result of their perceived cancer risk. Twenty-two (58%) of the 38 with a previous history of cancer who responded quantified their level of stress in life during the past four weeks as a result of their cancer risk was either "Moderate" to "Extremely" stressful, whereas 12 (32%) of the 38 participants without a previous history of cancer reported such levels. An additional 10 (26%) of the participants with a prior history of cancer and 13 (34%) of those without a prior history of cancer quantified their level of stress within the past four weeks as "Slightly" stressful. Compared with previous or other concurrent life stressors, 9 (24%) of the 38 participants without a cancer diagnosis who responded and 22 (56%) of the 39 with a cancer diagnosis reported their level of stress as "Moderate" to "Extremely" stressful. All the participants but one believed they were coping with their cancer risk "Fairly well" or "Extremely well." See Table 7 for specific health and psychosocial data.

Influence of Participants' Data on Health and Psychosocial Variables

The health and psychosocial variables were dichotomized into "Little" or "No difficulty" and "Moderate" or "High level of difficulty" to identify whether various demographic and medical information variables were factors that influences less favorable scores. The analyses of demographic and medical information variables included current age, age at diagnosis of cancer, educational level, marital status, occupation, age at which the patient became aware of the risk, number of years he or she was aware of the risk, proband cancer type, ranking of risk, number of family members affected by a cancer diagnosis, number of first-degree relatives with cancer, and number of family

TABLE 7. Differences in Scores Between Participants With and Without a Diagnosis of Cancer on Health Concerns and Psychosocial Adjustment

Instrument	With Cancer Diagnosis			Without Cancer Diagnosis			Wilcoxon Rank Sum Test	p-Value
	Number	Mean (SD)	Median (range)	Number	Mean (SD)	Median (range)		
<u>Medical Outcome Study (MOS)</u>								
Current health question ^a	38	3.5 (1.2)	4.0 (1.0-5.0)	38	3.8 (0.9)	4.0 (2.0-5.0)	-1.147	.251
Health compared to one year ago ^a	38	3.1 (1.1)	3.0 (1.0-5.0)	38	2.9 (0.6)	3.0 (2.0-4.0)	.894	.371
Prior health ^a	37	3.4 (1.5)	3.7 (1.0-5.0)	38	4.3 (1.1)	5.0 (1.7-5.0)	-3.150	.002
Health outlook ^a	39	3.4 (1.0)	3.3 (1.0-5.0)	38	3.8 (0.8)	3.8 (2.0-5.0)	-2.165	.030
Health concern ^b	39	3.1 (0.3)	3.0 (2.5-3.8)	38	3.1 (0.3)	3.0 (2.5-3.8)	.065	.949
Health distress ^b	39	2.8 (1.5)	2.5 (1.0-6.0)	39	2.1 (1.4)	1.5 (1.0-6.0)	2.996	.003
Role function ^b	36	1.0 (1.2)	0.5 (0.0-3.0)	39	0.6 (1.0)	0.0 (0.0-3.0)	1.736	.083
Social function ^b	38	2.7 (1.1)	2.5 (1.0-5.0)	38	2.2 (0.5)	2.0 (1.5-3.5)	1.923	.055
Family functioning ^a	37	5.0 (1.0)	5.0 (2.0-6.0)	38	5.0 (1.0)	5.0 (1.0-6.0)	.034	.973
Satisfaction with family life ^a	38	4.0 (1.0)	4.0 (2.0-5.0)	37	3.6 (1.0)	3.7 (1.0-5.0)	1.595	.111
Sexual functioning ^b	34	1.9 (1.0)	1.5 (1.0-4.0)	35	1.7 (1.0)	1.0 (1.0-4.0)	.985	.325
Relationship functioning ^a	35	4.1 (0.8)	4.3 (1.8-5.0)	36	4.1 (0.8)	4.3 (2.0-5.0)	-.330	.742
<u>Profile of Mood States (POMS-BI)</u>								
Negative affect ^b	35	0.0 (1.2)	-0.3 (-1.7-2.8)	33	-0.3 (1.2)	-0.7 (-2.0-2.5)	1.277	.202
Positive affect ^a	35	0.3 (1.5)	1.0 (-3.3-2.5)	35	0.6 (1.2)	0.8 (-2.2-2.3)	-.535	.593
Trait Anxiety Inventory (STAI) ^b	35	36.6 (9.0)	34.0 (22.0-54.0)	38	33.6 (10.1)	32.5 (20.0-59.0)	1.487	.137

^aHigh scores indicate a more favorable aspect of the concept.

^bLow scores indicate a more favorable aspect of the concept.

members with a cancer related to the type of cancer for which the individual is at increased risk. No significant differences in current health, health outlook, health concerns, health distress, social function, or sexual function were based on those demographic and medical information variables.

DISCUSSION

The four most significant findings included the following:

- a poor correlation between qualitative and quantitative self-assessment of risk,
- limited differences in psychosocial adjustment between participants with and without a diagnosis of cancer,
- significant correlations between trait anxiety and physical health and psychosocial variables, and
- an increased level of stress experienced as a result of participants' perceived risk status.

Participants also provided us with information about what they experienced as most difficult and most helpful in adjusting to their risk status.

The poor correlation between participants' qualitative assessments (reported on the basis of "no risk" to "extremely high risk") and quantitative assessments (reported on the basis of the percentages of their lifetime risk) provides support for Kelly's caution (1992) regarding the use of qualitative terms, such as average or high risk. Kelly warned that a high risk to one person does not constitute a high risk to others. Although this may underscore the importance of providing quantitative risks to people during counseling, it may be that perceived qualitative risk is a different psychological construct than the perceived mathematically calculated lifetime risk. Future research that explores the rationale for people's perceptions of their qualitative and quantitative risk after counseling would provide valuable information.

It was noteworthy that the majority of participants both with and without a cancer diagnosis identified their health as good to excellent and their health outlook as favorable, and they reported similar levels of concern about their health. The few differences between groups may have been a consequence of cancer patients learning that their illness was not as difficult as they had expected. As one patient put it: "I learned that fear is worse than cancer." However, the participants with cancer did identify more distress about their health than did those without cancer.

Our patients reported that one major adverse consequence of their viewing themselves as being at increased risk for cancer was a significant increase in

their general emotional stress: More than half of them reported that their level of stress had "increased" or "greatly increased." However, the objective mood-states score did not reflect mood disturbances. Only four patients with and four without a cancer diagnosis had positive affect scores that were less than 1.5 standard deviations from their group mean. Three patients with a cancer diagnosis and four without a cancer diagnosis had negative affect scores that were greater than 1.5 standard deviations from their group mean. This lack of objectively quantifiable, generalized emotional distress was previously reported by Lloyd et al. (1996), who emphasized the importance of examining cancer-specific stress in addition to generalized stress.

Participants reported similar responses for themselves and their families when asked about the impact that knowledge of their increased risk for cancer had on them and their families. Emotional stress and increased awareness of health were cited most often. Further studies involving family members would be useful to determine whether they would identify the same impact factors that patients do.

Our patients cited support from family and friends and accurate health information as helping them the most in their efforts to cope with their increased risk of cancer. This finding is consistent with previous reports (Chalmers, Thomson, & Degner, 1996; Mahon & Casperson, 1995) and provides useful data for clinical practice. Patients who are frustrated with family members who do not want to know or discuss the patient's risk status may benefit from talking with other people who are at increased risk. Cancer risk-assessment programs must provide consistent, accurate information that addresses the many issues related to a high-risk status (Chalmers, Thomson, & Degner, 1996; Mahon & Casperson, 1995).

Personality characteristics have been identified as important variables influencing outcomes in psychosocial research. In our study, trait anxiety was strongly correlated with positive and negative affect, health distress, and role limitations. These findings are consistent with those of Lazarus (1991), who identified a correlation between anxiety and poor performance.

Demographic and medical information was not found to play a significant role in relation to adverse scores on the majority of the health and psychosocial variables. The small sample size made it difficult to detect all but large differences between groups.

Because a significant number of statistical tests were conducted, some statistically significant findings are likely to be spurious. However, identification of these variables provides hypotheses that can be used to design future studies.

Finally, although the majority of participants reported that their level of stress had increased greatly as a result of their risk status, the majority also reported no impact on their emotional stability. This finding points to the

need to use a measure that is specific to the distress resulting from cancer risk in addition to global indexes of distress. Interestingly, few differences existed between participants with and without a diagnosis of cancer. Both groups identified accurate health information and emotional support as key strategies in managing their risk. The differences between quantitative and qualitative interpretations of risk point to the need for reporting risk levels in quantitative terms. Our results add useful data to the ongoing effort to understand and to address satisfactorily the psychosocial needs of people at increased genetic risk for cancer.

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